Community of Practice on Traumatic Brain Injury

Transcript: Webinar 2: Data Sources, Challenges, and Successes
October 15, 2013. 3:00-4:00 P.M. ET

WE ARE RECORDING THIS AND WE'LL MAKE IT AVAILABLE TO YOU AFTER THE SESSION.
I'M GOING TO PASS IT BACK OVER TO REBEKAH.
I WANT TO GET THE BALL ROLLING ABOUT WHY DATA WHY IS DATA SO IMPORTANT.
I THINK WE ALL KNOW IN THE PUBLIC HEALTH FIELD WE KNOW IT'S REALLY IMPORTANT BUT WE'RE STARTING WITH DATA BECAUSE THAT'S HOW YOU NEED TO START ANY PROGRAM.
THAT'S WHERE YOU START TO DESIGN THINGS AND HAVE TO COLLECT THE INFORMATION AND THE DATA.
SO THAT'S WHY OUR FIRST REALLY MEETING OF THE TRAUMATIC BRAIN INJURY COMMUNITY PRACTICE IS ON
DATA.
SO DATA HELPS US IDEA THE
PROBLEM [INDISCERNIBLE].
FROM THERE, WE START TO DEVELOP
A ROBUST INTERVENTION, SUPPORT
POLICY AND LEGISLATION,
LEGISLATIVE DECISIONS.
MEASURE THE IMPACT THAT YOUR
PROGRAM IS HAVING, AND INFLUENCE
DECISION MAKERS TO ASSURE
SUSTAINABILITY OF YOUR PROGRAM.
DATA PROVIDES THE RATIONALE AND
JUSTIFICATION FOR
DECISION-MAKING, SO THAT'S WHY
WE'RE STARTING WITH DATA.
ACCORDING TO THE CDC, THERE ARE
THREE MAIN COMPONENTS AND TENETS
OF A GOOD DATA COLLECTION
PROGRAM FOR TRAUMATIC BRAIN
INJURY.
 THESE INCLUDE EMERGENCY
DEPARTMENT VISIT DATA,
HOSPITALIZATION DATA AND DEATH
DATA.
IN ADDITION TO RAW NUMBERS ON
THESE CIRCUMSTANCES OR INSTANCES OF TRAUMATIC BRAIN INJURY, THIS DATA SHOULD ALSO CAPTURE AGE, SEX, RACE AND EVEN MECHANISMS AND CIRCUMSTANCES RELATED TO THE TRAUMATIC BRAIN INJURY. THAT WILL HELP GIVE US A MORE ROBUST PICTURE OF WHAT IS ACTUALLY HAPPENING IN TERMS OF TBI DATA.

THERE ARE A COUPLE OTHER DATA COLLECTION MECHANISMS OR SOURCES THAT YOU CAN USE FOR TRAUMATIC BRAIN INJURY SUCH AS ACUTE REHABILITATION. IT'S A GOOD DATA SOURCE BUT IT CAN BE HARD TO CAPTURE. ALSO CRIMINAL JUSTICE AND MANY OTHERS.

BUT ACCORDING TO THE CDC, THESE ARE THE THREE MAIN COMPONENTS YOU REALLY NEED IF YOU'RE GOING TO HAVE A ROBUST DATA COLLECTION SYSTEM FOR TBI. I DON'T WANT THIS TO BE BORING
INFORMATION ABOUT DATA, SO I
THOUGHT YOU WOULD LIKE TO SEE
WHAT THE NATIONAL AVERAGES ARE
ON THESE DATA.
SO THE EMERGENCY DEPARTMENT
VISIT FOR TRAUMATIC BRAIN INJURY
ARE 681 PER 100,000.
HOSPITALIZATIONS ARE 96.6 PER
100,000 AND FATAL TRAUMATIC
BRAIN INJURIES IS 16 IT 84 PER
100,000.
THIS COMES FROM HEALTHY
PEOPLE.GOV 20/20 WHICH IS A
REALLY INTERESTING SOURCE.
THEY PROVIDE ALL SORTS OF
INTERESTING WAYS TO CUT AND LOOK
AT THE DATA.
SO IF YOU HAVE A CHANCE, I'D AN
COURAGE YOU TO GO CHECK THAT
OUT.
AND JUST TO FOLK ON THE
COMMUNITY PRACTICE, HERE ARE THE
RATES FOR ALL OF YOUR STATES
ACCORDING TO WHISKERS.
THIS IS FROM THE NEW MAPPING
MODAL DETHEY HAVE.

THIS IS FROM 10.24 IN NEW JERSEY TO 23.35 IN MISSOURI.

THE AVERAGE FATALITY RATE FOR TRAUMATIC BRAIN INJURIES IN THE COMMUNITY OF PRACTICE IS 18.35 PER 100,000.

SO THAT IS SLIGHTLY HIGHER THAN THE NATIONAL AVERAGE OF 16.84 NATIONALLY.

FIVE STATES IN THE COMMUNITY OF PRACTICE ARE UNDER THE NATIONAL AVERAGE AND TEN ARE OVER IT.

IF YOU WANT TO FILED OUT MORE ABOUT THE FATALITY RATE IN THE 0-24 AGE RANGE YOU SHOULD CHECK OUT THE SHEETS I WAS TALKING ABOUT.

I JUST BRINGING THOSE DOWN AND LET YOU KNOW WHAT THAT RATE IS OR YOU CAN GO TO THE MAPPING MODALITY AND FIND OUT THERE.

IF YOU WANT MORE INFORMATION ABOUT THE RANKING AMONG THE COMMUNITY OF PRACTICE IS ALL
THERE BUT I'M PERFECTLY WILLING TO SHARE THAT INFORMATION WITH YOU, JUST LET ME KNOW.

SO, THERE ARE A COUPLE DATA GAPS IN EVEN WITH THOSE THREE COMPONENTS THAT THE CDC STILL RECOMMENDS.

EXISTING TRAUMATIC BRAIN INJURIES, THINGS THAT HAVE HATCHED IN THE -- HAPPENED IN THE PAST.

TBI IS NOT RESULTING IN AN ED VISIT ARE NOT CAPTURED.

WITH A LOT OF THE POLITICAL WILL HAPPENING AROUND SPORTS CONCUSSIONS, WE'RE SEEING THOSE HOSPITALIZATIONS AND ED VISITS ARE INCREASING.

I THINK BECAUSE OF THE AWARENESS OF CONCUSSION AND TRAUMATIC BRAIN INJURIES WE SEE THAT NUMBER GO UP.

IT'S A GOOD THING WE HAVE A BETTER IDEA OF THE SCOPE.

ONCE THE REAL SCOPE IS KNOWN WE
CAN WORK TO RULES IT.

ANOTHER DATA IS ALSO FROM INDIAN
HEALTH SERVICES OR VETERAN
HEALTH SERVICES.

THOSE MAY NOT BE CAPTURED BY THE
FULL STATE SYSTEM.

SO I DO HAVE A POLL QUESTION
ABOUT WHICH TBI DATA YOU'RE
COLLECTING AND WHETHER OR NOT
YOU COLLECT FROM THOSE SYSTEMS,
WHICH ARE NOT NECESSARILY LISTED
IN THE, THAT IT MIGHT BE A GAP.

WHETHER OR NOT YOU ARE
COLLECTING THAT INFORMATION
WHICH IS OFTEN THE GAP.

ON THIS THING IN FRONT OF YOU
SEE THE FOLLOWING TIMES OF TBI
DATA ARE COLLECTED IN YOUR
STATE.

GO AHEAD AND COLLECT ON THOSE.
YOU CAN CLICK AS MANY AS YOU'D
LIKE.

ALREADY.

THAT LOOKS PRETTY STABLE.

SO ABOUT 95% ARE COLLECTING
DEATH DATA, 85% HOSPITALIZATION,
AND ABOUT 76 EMERGENCY
DEPARTMENT.

GREAT.

BAYLY, CAN YOU PUT UP THE NEXT
POLL ABOUT COLLECTING FROM
INDIAN HEALTH SERVICES AND
VETERAN SERVICES.

>> SURE.

>> THIS IS JUST TO GET A SENSE
OF IF YOU KNOW WHETHER OR NOT
THOSE GAPS ARE BEING FILLED IN
YOUR DATA SYSTEM OR IF THERE
MIGHT BE A COMPONENT THAT YOU
WOULD WANT TO GO HOW THE AND
SEEK OUT MORE INFORMATION ON, IF
THERE’S ANY WAY TO STREAMLINE
THOSE INFORMATION SERVICES OR
INFORMATION DATA CENTERS IN YOUR
STATE.

AND IF YOU DO HAVE AN OTHER, IF
THERE’S SOME OTHER DATA SOURCE
THAT MIGHT NOT BE CAPTURED SO
FAR IN THESE COMPONENTS, PLEASE
FEEL FREE TO WRITE THAT DOWN.
GREAT, OKAY.
SO IT LOOKS LIKE ABOUT 36% OR
FOUR GROUPS ARE COLLECTING
INFORMATION FROM PRODUCTS AND
SERVICES.
NONE FROM INDIAN HEALTH SERVICES
AND MANY ARE SELECTING FROM
OTHER SOURCES SUCH AS TRAUMA
REGISTRIES.
MOSTLY FROM THE REGISTRY.
ALL RIGHT GREAT, THAT'S REALLY
INTERESTING INFORMATION.
THAT WILL HELP US REALLY PUT
TOGETHER SOME INFORMATION ABOUT
WHAT PEOPLE ARE DOING IN THEIR
STATES AROUND DATA.
SO THERE'S JUST A COUPLE DATA
SOURCES THAT I WANTED TO PULL
YOUR ATTENTION TO.
CDC HAS LAUNCHED TWO NEW
MODALITIES.
IF YOU CLICK ON THE LINK THEY
HAVE A NIFTY NEW FUNCTION THAT
YOU CAN LOOK AT AVERAGES FROM
2004 TO 2010 ON TRAUMATIC BRAIN
INJURIES, IT’S ALL FATALITY DATA.

YOU CAN LOOK BY STATE, AGE, RATES, MECHANISM ALL SORTS OF THINGS SPECIFICALLY ABOUT TRAUMATIC BRAIN INJURY.

AND IT’S VERY INTERESTING.

THEY DID THE SAME THING WITH COST DATA, SO IF YOU'RE LOOKING FOR COST DATA SPECIFIC TO A POPULATION TO YOUR STATE, TO AN AGE RANGE, I WOULD CHECK OUT THAT COST OF INJURY REPORT WHICH ALSO BREAKS IT DOWN SPECIFICALLY TO TBI.

IF YOU NEED ANY HELP FIGURING OUT THAT SYSTEM, FEEL FREE TO GIVE ME A CALL AND I CAN WALK OTHER THROUGH WITH YOU.

THERE’S HEALTHY PEOPLE 20/20 WHICH HAS INDICATORS IVP2.1-2.3.

SO THOSE INDICATORS ARE SPECIFIC CLEAZ ABOUT DEATH, DD VISITS AND HOSPITALIZATIONS.

YOU HAVE TO USE BODY REGION BY
NATURE OF INJURY.
SO THAT'S ANOTHER INTERESTING
ONE TO LOOK AT, AND THAT IS HOW
WE HAVE THE INFORMATION THAT
THOSE VISITS AND HOSPITALIZATIONS
ARE ACTUALLY GOING UP NOT DOWN.
WE ARE FAR OFF FROM ACHIEVING
THE GOAL OF PEOPLE FROM 20/20.
THE LAST ONE THAT'S HEALTH
INDICATORS.GOV WHICH ALSO
INDIVIDUALS A MODALITY.
THE ONE CDC GOES DOWN TO THE
COUNTY LEVEL AND THIS ONE STATES
AT THE STATE LEVEL.
IT'S INTERACTION AND YOU CAN
LOOK AT WHERE YOUR STATE FALLS
IN COMPARISON TO SOME OTHER
STATE.
GO AHEAD AND CHECK THOSE OUT
WHEN YOU HAVE TIME, IF YOU'RE
INTERESTED, THEY ARE FUN AND
INTERESTING IF YOU'RE A DATA
NERD LIKE I AM.
SO THE REAL CRUX OF OUR
CONVERSATION IS CENTERED AROUND
WHAT IS THE DIFFERENCE BETWEEN A
REGISTRY AND A SURVEILLANCE
SYSTEM.
WE TALKED ABOUT THE COMPONENT
ABOUT TBI DATA.
WHAT DO WE REALLY MEAN BY A
REGISTRY VERSUS A SURVEILLANCE.
WHAT ARE THE BENEFITS OF EACH.
WHAT ARE THE NEEDS, WHAT ARE WE
LOOKING TO DO WITH THAT DATA
THAT WE KNOW IS SO IMPORTANT TO
COLLECT.
SO WE DO HAVE EXAMPLES OF A
REGISTRY AND A SURVEILLANCE
SYSTEM THAT WILL TALK TO US
TODAY.
SO MOVING ON, OUR SURVEILLANCE
SYSTEM, ACTUALLY THAT FIRST WEB
LINK BOX CALLED TRAUMATIC BRAIN
INJURY IN THE UNITED STATES, THE
REGISTRY AND DATA SYSTEMS HAS
VERY GOOD INFORMATION THAT
OUTLINES WHAT THE DIFFERENCE IS
BETWEEN A SURVEILLANCE SYSTEM
AND A REGISTRY.
SO IF YOU'RE LOOKING FOR MORE IN-DEPTH INFORMATION OR IF YOU WANT TO REVIEW WHAT I'M SAYING DURING THIS CALL, YOU CAN GO BACK AND LOOK AT THIS REPORT. IT'S SIMPLE AND EASY TO READ AND COMPREHENSIVE.

SO THE DEFINITION OF A SURVEILLANCE SYSTEM IS ROUTINE ONGOING COLLECTION OF DATA ABOUT PEOPLE WHO STAY AT TDI.

THE MAIN REASON FOR HAVING A SURVEILLANCE SYSTEM IS DATA COLLECTION AND ANALYSIS.

ON AVERAGE, THE CDC PROVIDES FUNDING FOR TBI SURVEILLANCE SYSTEM AROUND $80,000 PER YEAR.

IT'S A FAIRLY HIGH INTENSIVE COLLECTION PROCESS.

AND THAT'S JUST WHAT ON AVERAGE WHAT THE CDC THINKS IT SHOULD COST.

THE DEFINITION OF A REGISTRY IS A COLLECTION OF DATA ABOUT A PARTICULAR GROUP OF PEOPLE WHO
SHARE A COMMON PERSONAL CHARACTERISTIC, FOR EXAMPLE DEVELOPMENT OF THE SAME DISEASE OR IN THIS CASE TRAUMATIC BRAIN INJURY.

SO A REGISTRY ALSO COLLECTS THE DATA BUT INSTEAD OF JUST ANALYZING THAT DATA, THEY LEVERAGE THAT DATA WITH PERSONAL IDENTIFICATION INFORMATION TO LINK THOSE PEOPLE WHO HAVE SUSTAINED A TBI TO SERVICES. OFTEN TIMES REGISTRIES PROVIDE DATA ELECTION TO CHECK IF PEOPLE DID GET THOSE SERVICES, WHAT WAS THE IMPACT OF THE SERVICE, HOW PEOPLE FELT ABOUT THE SERVICE AND REALLY ASSESS THE IMPACT OF THEIR WORK.

DEPENDING ON THE DEPTH AND BREADTH OF THE REGISTRY, IT CAN BE MORE EXPENSIVE, SO IN FLORIDA IN 2005, THEIR REGISTRY SYSTEM WHICH WAS JUST, IT WAS BASICALLY A SURVEILLANCE PROGRAM WITH
PERSONAL IDENTIFICATION both
$75,000 a year but in Virginia
it was $125,000 a year.
I'm not sure that either of
those programs are currently
ongoing that has changed a lot
since that report was released
but you can look up information
on those registries and that's
just a sample of the kind of
cost data, cost information that
you might be curious about.
All right.
Now that we've heard what the
main distinction between a
registry and a surveillance
system is, I'm going to pull up
another poll.
See if you can pull up that last
poll.
It says does your state have a
registry or surveillance system
or neither.
You need just a second for that.
All right.
SO IT LOOKS LIKE ONLY TWO STATES HAVE A TBI REGISTRY.
THERE ARE ABOUT NINE WITH THE SURVEILLANCE SYSTEM, SIX WITH BOTH, AND SEVEN WITH NEITHER.
ALL RIGHT.
THAT'S REALLY INTERESTING INFORMATION TO HAVE.
GREAT.
NOW, I'M GOING TO TURN THING OVER TO MICHAEL BOWER FROM NEW YORK WHO IS GOING TO TALK ABOUT HIS VERY ROBUST DATA SURVEILLANCE SYSTEM IN NEW YORK.
SO MICHAEL, WHENEVER YOU'RE READY, YOU CAN TAKE OVER THE FLOOR.
>> GREAT.
HI, EVERYBODY.
SO WHAT I'M GOING TO DO TODAY IS I'VE GOT SORT OF A LAST MINUTE REQUEST WITH RENE NOT BEING ABLE TO PARTICIPATE SO I THOUGHT THE BEST THING I COULD DO FOR INFORMATION FOR EVERYBODY IS
TAKE AN OLD, COUPLE YEARS OLD
PRESENTATION I DID AT THE
COUNCIL STATE TERRITORY
EPIDEMIOLOGIST ANNUAL MEETING.
I'VE CUT IT DOWN A LITTLE BIT
AND I'M NOT GOING TO TALK ABOUT
THE NITTY GRITTY OF THE DATA AND
WHAT WE FOUND BUT MORE ALONG THE
LINE WHAT WE DID WITH THE DATA,
HOW WE USED THE DATA, HOW WE
ANALYZED THE DATA AND YOU KNOW
SORT OF MORE OF A CONCEPTUAL
LOOK AT OUR INJURY SURVEILLANCE
ON TRAUMATIC BRAIN INJURIES.
WE DO NOT HAVE A BRAIN INJURY
REGISTRY.
IT WOULD BE GREAT IF WE DID, BUT
WE DO NOT HAVE ONE HERE IN NEW
YORK.
ALSO, THIS PRESENTATION'S A
COUPLE YEARS OLD, THE DATA'S A
COUPLE YEARS OLD BUT IT'S STILL,
YOU KNOW, IT'S STILL FINE DATA
TO LOOK AT.
GIVE YOU AN IDEA OF WHAT'S GOING
ON.

THE TRAUMATIC BRAIN INJURY THAT ARE NOT RANDOM AND CONTROLLED BY THE STATE BUT THEY OCCUR IN PREDICTABLE PATTERN, RECOGNIZABLE RISK FACTORS AMONG IDENTIFIABLE POPULATIONS. SO TBI IS PREVENTIBLE. THIS PRESENTATION WILL DEMONSTRATE HOW TO TRY TO PREDICT AND PREVENT THESE INJURIES. THE TBI, AS YOU ALREADY HEARD ABOUT THE MAIN THREE FROM THE CDC, DEATH DAY WAS SORT OF THE TIP OF THE ICEBERG. THE NUMBERS ARE LOWER BUT OBVIOUSLY A VERY SEVERE OUTCOME. HOSPITALIZATION DATA WHICH ARE STAGES 24 HOURS OR GREATER IN A HOSPITAL SO IT'S PRETTY SEVERE RESULTS. EMERGENCY DEPARTMENT DATA VISITS. AND OTHER MEDICAL TREATED OR
UNTREATED WHICH IT'S DIFFICULT TO CAPTURE.
WE DON'T REALLY HAVE A REGISTRY,
NO GREAT WAY TO CAPTURE PEOPLE TREATED AT A DOCTOR'S OFFICE,
PEOPLE TREATED AT NURSE'S OFFICE, FORCED CONCUSSIONS ARE THE MAIN ISSUE THESE DAYS.
AND ALTHOUGH WE CAN USE SOME VARIABLES IN HOSPITALIZATION,
TBI DATA IS SORT OF SURROGATE FOR THAT.
THERE IS SOME SPORTS-RELATED CODES.
WE REALLY CAN'T TELL JUST BY USING THAT DATA SET WHETHER IT WAS A SCHOOL-RELATED SPORTS CONCUSSION AND ITEM, SOMETHING LIKE THAT.
BUT THERE ARE SOME STATES THAT ARE WORKING TOWARDS LEARNING MORE ABOUT THAT DATA.
SOME OF THE THING WE DO WITH OUR TBI SURVEILLANCE SYSTEM,
HOSPITALIZATION DATA, WE HAVE UP
TO 2011.

WHEN I DID THIS PRESENTATION WE HAD 2008.

WE CAN LOOK AT HOSPITALIZATIONS, SEE THEY ARE INCREASING OVER TIME.

SAME WITH THE ED DATAS.

ONE THING ABOUT TRAUMATIC BRAIN INJURY EMERGENCY HOSPITAL VISITS THESE ARE PEOPLE GENERALLY TREATED AND RELEASED, BUT THEY CAN BE TRANSFERRED TO ANOTHER FACILITY FOR THE MOST PART TRIGGER AND RELEASE.

WE LOOKED IF -- LOOKED AT THE DATA.

THERE’S REALLY A LARGE INCREASE.

THE INKRARYLS YOU SEE HERE WE STARTED COLLECTING TBI DATA IN 2005 DOESN’T COMPARE AT ALL TO THE INCREASE WE’VE SEEN IN THE LAST FEW YEARS WHICH HAS REALLY JUMPED.

I DO AGREE IT HAS A LOT TO DO WITH THE AWARENESS OF HAVING A BRAIN INJURY, A CONCUSSION TEST
TO HAVE TREATED.

OBVIOUSLY GENDER DIFFERENCES IS
ANOTHER THING WE LOOK AT A LOT.
MALES ARE MORE LIKELY TO DIE
FROM A TBI, HOSPITALIZE FROM A
TBI AND TREATED ED FOR TBI IN
NEW YORK.
AGAIN I'M NOT LOOKING AT THE
ACTUAL NUMBERS IN THIS
PRESENTATION AS MUCH AS JUST
SORT OF GIVING AN OVERVIEW OF
WHAT WE DO WITH OUR DATA.
ANOTHER THING THAT WE LOOK AT
ARE WHICH COUNTIES HAVE THE
HIGHEST NOT JUST NUMBER BUT THIS
PICTURE OF NEW YORK STATE.
AND IT'S AGE-ADJUSTED RATES PER
100,000 COUNTIES AND QUARTILES,
THE DARKER ONES WITH THE HIGHEST
TBI RATES.
SO WE CAN SORT OF LOCATE WHAT
COUNTIES IN NEW YORK STATE HAVE
THE HIGHEST TBI RATES.
THIS IS SIMILAR MAP AT THE
EMERGENCY DEPARTMENT DATA
LOOKING AT THEM, THE AGE
ADJUSTED RATES IN DIFFERENT
COUNTRIES.
DIFFERENT COUNTIES.
CHARGE INFORMATION IS ALSO
SOMETHING THAT IS VERY
IMPORTANT, PEOPLE ALWAYS LOOK AT
TBI'S IN PARTICULAR ARE VERY
COSTLY INJURY.
AND WE CAN LOOK AT, YOU CAN EVEN
LOOK AT THE TOP COUPLE THERE.
YOU CAN SEE THE MEAN CHARGE FOR
HOSPITALIZATION STAY IN NEW YORK
AND THOSE YEARS IT'S 37,000 FOR
TBI FOR NON-TBI WITH ONLY
28,000.
AND THE MEAN HOSPITAL STAY WAS
SEVEN DAYS AND IT WAS A YEARLY
AVERAGE OF SEVEN MILLION DOLLARS
FOR A TBI.
OVER THOSE THREE YEARS.
WE CAN LOOK AT THE SAME FOR ED
VISITS ALSO.
AND 80 VISITS OBVIOUSLY ARE
USUALLY MUCH CHEAPER.
ANOTHER THING THAT WE OFTEN LOOK AT IS AGE AND WE TAKE A LOOK AT BOTH NOT JUST THE NUMBERS BUT THE RATES AT EACH AGE GROUP.

AS YOU CAN SEE IF YOU LOOK AT THIS SLIDE LOOKING AT DEATHS, OLDER ADULTS HAVE HIGHER NUMBER AND HIGHER RATES DUE TO TRAUMATIC BRAIN INJURY.

THE 20-24 YEAR OLD AGE GROUP HAS A BIT OF A SPIKE ALSO.

HOSPITALIZATIONS, IT'S INTERESTING SLIDE LOOKING AT THE AGE ACROSS THE AGE, YOU CAN SEE AGAIN 65 AND UP HAVE THE HIGHEST NUMBER AND RATE.

BUT IF YOU LOOK AT THE YOUNGER AGE GROUPS THE ZERO TO ONE, THEY HAVE REAL HIGH RATE OF HOSPITALIZATIONS DUE TO TRAUMATIC BRAIN INJURY.

OBVIOUSLY THERE'S ONLY ONE YEAR OF AGE THERE, ARE SO THE NUMBERS ARE LOWER BUT THE RATE IS VERY, IS THE SECOND HIGHEST RATE AMONG
ALL THOSE AGE GROUPS.
SIMILARLY WITH ED VISITS, THE
CHILD 0-1 AND 1-4 HAVE VERY HIGH
RATES IN THE NUMBERS OF ED
VISITS.
PARENTS ARE MAKING SURE THEIR
KIDS ARE CHECKED AT THE YOUNGER
GROUPS, IF THEY BANG THEIR HEAD
AND 0-1 YOU’RE LOOKING AT THING
AROUND SHAKEN BABY SYNDROME AND
OTHER ASSAULT-RELATED INJURIES.
ANOTHER THING WE OFTEN DO WITH
OUR DATA IS LOOK AT WHAT WAS THE
CAUSE OF THE TRAUMATIC BRAIN
INJURY.
IN RED ARE HOMICIDE AND SUICIDE
ON THIS TABLE.
THE STARS ARE JUST THE NUMBERS
ARE, THE AVERAGE IS LESS THAN
THREE AND IF WE HAVE A THREE
YEAR AVERAGE OF LESS THAN THREE
WE DON’T REPORT THAT NUMBER DUE
TO CONFIDENTIALITY REASONS.
SO SOME OF THOSE NUMBERS WOULD
BE FILLED IN TOO LOW AT THE
DESK.

But as you can see the runs in yellow are all those related through motor vehicle incident ones are the pedestrian, so that's a major issue and falls, particularly as a person age becomes a real large issue. Hospitalizations we can do the same thing.

Falls right across the board is a leading cause for traumatic brain injury except in the 15-19 and 20-24 age group where motor vehicle crashes and assaults are the first and second leading causes of traumatic brain injury.

Learning what are the leading causes is very important in looking at leading causes by ages and by gender. We really get to learn what's going on.

Similar slide with emergency
DEPARTMENT VISITS AND AGAIN
FALLS EARLY AND OLDER ARE VERY
HIGH FOR TRAUMATIC BRAIN INJURY.
STRUCK IS HIGH FOR 15-19 AND AWE
-- ASSAULTS ARE HIGH IN THE
MIDDLE EAST GROUPS.
THAT SORT OF FOLLOWS IN WE CAN
LOOK AT THE END WHETHER IT WAS
ASSAULT OR HOMICIDE AND WE CAN
LOOK AT THE MALE VERSUS FEMALE
FOR UNINTENTIONAL.
PERCENT OF DEATHS ARE PRETTY
SIMILAR.
WE LOOK AT HOMICIDE FEELS ARE
MORE LIKELY TO DIE DUE TO A
TRAUMATIC BRAIN INJURY HOMICIDE
AND SUICIDE MALES ARE MORE
LIKELY TO COMMIT SUICIDE BY USE
OF MEANS THAT CAUSES TRAUMATIC
BRAIN INJURY.
HOSPITALIZATIONS, THE MALES
ACROSS THE BOARD HAVE THE
LEADING, HIGHER UNINTENTIONAL
ASSAULT AND SELF INFLECTED
INJURIES.
AND ED VISITS, UNINTENTIONAL FEELS HAVE A SLIGHTLY HIGHER PERCENTAGE THAN MALES WITH THE ASSAULT AND SELF INFlicted MALES.

ANOTHER THING THAT WE CAN LOOK AT WITH OUR DATA IS THE PLACE OF INJURY AND THIS SLIDE IS BROKEN OUT BETWEEN 0-64 AND 65 PLUS.

THE LARGER PRESENTATION I DID REALLY DID FOCUS A LOT ON FALL AND DID SOME MORE WORK AROUND WHAT WE THOUGHT ON FALLS.

THIS WAS JUST ONE OF THEM I FOUND OF INTEREST.

IF YOU LOOK AT THE 65 PLUS AGE GROUP, 55% OF THOSE ARE FALLING AT THEIR HOME AND 0-64, 31% ARE FALLING AT THEIR HOME.

BUT WE CAN ALSO LOOK AT DISCHARGE LOCATION AND YOU CAN SEE THAT ALL, YOU CAN SEE A LARGE NUMBER 65 PLUS ARE GETTING DISCHARGED THROUGH NURSING FACILITIES SO THERE'S ADDITIONAL
COSTS AND CARE NEEDED WHETHER IT'S A LONG TERM OR SHORT TERM REHAB STAY FOR THE 65 PLUS. ZERO TO 64 FOR THE MOST PART ARE BEING DISCHARGED.

ANOTHER DATA SET THAT WE USE IN NEW YORK TO REALLY UNDERSTAND TRAUMATIC BRAIN INJURIES IS OUR FRESH DATA EVALUATION SYSTEM COMMONLY KNOWN AS CODES. THIS IS A LINK DATABASE.

THIS MATCHES RECORDS FROM OUR ACCIDENT INFORMATION SYSTEM WHICH IS DEPARTMENT OF MOTOR VEHICLES, POLICE AND MOTOR CRASH REPORT DATA AND WE LINK IT TO OUR PRE HOSPITAL CARE OR EMS DATA AND WE LINK IT TO OUR HOSPITAL DISCHARGE AND EMERGENCY DEPARTMENT DATA.

AND SO THIS DATA IS, PROVIDES A WEALTH OF INFORMATION ON MOTOR VEHICLE TRAFFIC AND AGAIN AT THE MEETING, THE LARGER PRESENTATION I DID A LOT MORE FOCUSING ON
MOTOR VEHICLE.

BUT WHEN YOU PULL IN THAT EXTRA PIECE OF SURVEILLANCE, IF YOU'RE ABLE TO LINK AND GET ACCESS TO YOUR DEPARTMENT OF MOTOR VEHICLE DATA, YOU CAN LEARN ABOUT THE TYPE OF CRASH OR CONTRIBUTING FACTORS.

AND THIS LOOKS AT A TOTAL NUMBER OF PEOPLE INVOLVED, PEOPLE HOSPITALIZED AND THOSE HOSPITALIZED WITH THE TBI AND THE CONTRIBUTING FACTORS OF THE CRASH, ALCOHOL, SPEED, DISTRACTED DRIVE, FAIL TO YIELD, FOLLOWING TOO CLOSELY TRAFFIC CONTROL DISREGARD AND YOU CAN SEE THAT ALCOHOL AND SPEED RELATED HAVE THE TWO HIGHEST PERCENT HOSPITALIZATIONS THAN THE TBI.

YOU CAN ALSO LOOK IN THE POLICE CRASH REPORT DATA AT THE TYPE OF CRASH.

THIS IS ALSO IN THE
HOSPITALIZATION ED SORT OF THE
STAND-ALONE, BUT BRINGING THE
DIFFERENT VARIABLES THAT ARE IN
THE CRASH REPORT DATA ALSO
LEARNS TO HELP ABOUT
CONTRIBUTING FACTORS.
IT HAS A LOT OF OTHER
INFORMATION SUCH AS WEATHER
CONDITION AND A VARIETY OF OTHER
INFORMATION THAT YOU CAN'T FIND
IN HOSPITALIZATION ED DATA BUT
ARE IN AT LEAST THE CRASH
REPORTS.
WE CAN SEE
BICYCLISTS MOTORCYCLES
OCCUPANTS -- BICYCLE UNDER THE
AGE OF THE AGE OF 14 MUST WEAR
AN APPROVED HELMET BUT NOT IF
THEY'RE OLDER.
AND ALL MOTORCYCLE MUST WEAR A
DOT APPROVED HELMET.
IN THE DATA SET AT THE MOMENT
IT'S BEING CHANGED IS WHETHER
THEY WEAR A HELMET OR NOT BUT WE
MADE SOME CHANGES TO OUR CRASH
REPORT DATA SO THE OFFICER NEEDS TO MENTION WHETHER IT'S AN APPROVED HELMET OR NOT AND THAT WILL HELP US REALLY UNDERSTAND.

MOST OF THE DATA COMES IN WITH THE MOTORCYCLISTS WEARING A HELMET BUT YOU DON'T KNOW IF IT'S AN APPROVED HELMET OR NOT.

OTHER THING OF INTEREST THAT WE CAN'T LEARN JUST FROM HOSPITALIZATION OR ED OR DEATH DATA DOESN'T HAVE INFORMATION SO WE CAN LOOK AT CHILD RESTRAINT USE, WHETHER THE USE OF CHILD PASSENGER SAFETY SEAT OR SEATBELT USE, WHETHER THEY HAD A SEAT BELT OR NOT WEARING A SEATBELT WE CAN LOOK AT SEATING POSITION IN THE VEHICLE.

OUTSIDE OF DRIVER AND HOSPITALIZATION ED DATA, WE DON'T KNOW WHAT THEIR SEATING POSITION WAS.

WE DO KNOW THEY WERE A DRIVER OR NOT.
SO HAVING THIS CRASH DATA IN THERE, WE CAN SEE RESTRAINT.
THOSE WITHOUT IT, A SEATBELT ARE MUCH HIGHER THAN THE PERCENTAGE OF TBI THAT HAD RESTRAINT USE.
THIS MORE LIKELY TO REQUIRE HOSPITALIZATION IF NOT USED FOR STRAINING.
THE AVERAGE HOSPITAL CHARGE IS OVER $2,000 HOUR AND THREE TIMES MORE LIKELY -- THESE ARE ALL IMPORTANT THINGS WE HAVE IN THIS LITTLE DISCUSSION ABOUT OUR SEATBELT LAW IN NEW YORK AND WHY WE SORT OF LOOK AT THESE DIFFERENT THINGS AS WE ALL KNOW SEATBELTS ARE HELPFUL AND SEATBELT USE IS GREAT.
SO IN CONCLUSION, WE CAN LOOK AT THE EXTENT OF THE DATA, THE
INCIDENT, THE RATES.
WE CAN LOOK AT PATTERNS OF RISK FACTORS, POPULATION GREATEST AT RISK.
WE CAN DO SOME TIME ANALYSIS, WE CAN LOOK AT OTHER INFORMATION, PARTICULARLY IF WE'RE LOOKING AT CRASH DATA, WE CAN LOOK AT THE STUFF I JUST TALKED ABOUT.
HOSPITALIZATION DATA HAS A LOT OF DIFFERENT THING WE CAN LOOK AT TO REALLY UNDERSTAND THE ISSUE.
THE EXTENT OF INCIDENCE AND PREVALENCE WE DON'T HAVE A REGISTRY, WE DON'T COLLECT DATA AT DOCTORS OFFICES, WE DON'T HAVE DATA AT THE SCHOOL NURSES. WE DON'T HAVE A LOT OF DATA THAT WOULD BE MUCH MORE HELPFUL FOR US TO REALLY UNDERSTAND THE PROBLEM.
THE DATA WE HAVE IS VERY GOOD AND IT DOES HELP SHOW US THE PATTERN OF OCCURRENCES AT TBI.
WE CONTINUE TO INCREASE OUR
KNOWLEDGE OF TBI OCCURRENCE AND
WE DO PREVENTION PROGRAMS ON
EVIDENCE-BASED STRATEGIES AND
BEST PRACTICES TO HELP PREVENT
TRAUMATIC BRAIN INJURIES AMONG
NEW YORKERS.

SO MY CONTACT INFORMATION.

AND HOPEFULLY THAT WAS A NICE
OVERVIEW OF SORT OF WHAT WE ARE
DOING WITH OUR SURVEILLANCE
SYSTEM.

AND I'M NOT SURE IF YOU HAVE
QUESTIONS NOW OR LATER.

>> I THINK WE'LL TAKE QUESTIONS
AT THE END JUST TO MAKE SURE WE
CAN GET ALL THE PRESENTATIONS
IN.

BUT THAT WAS GREAT, REALLY
INTERESTING TO HEAR ABOUT.

THANKS SO MUCH FOR YOUR
PRESENTATION.

NOW WE'RE GOING TO TURN THINGS
OVER TO MARK KINDE OF MINNESOTA
WHO WILL TALK ABOUT THE REGISTRY
SYSTEM THERE.

SO MARK, ARE YOU ON THE LINE?

>> HEY, I AM HERE AS ARE A
NUMBER OF MY COLLEAGUES.

AND SO IT’S WONDERFUL TO BE IN
MINNESOTA AND WONDERFUL TO BE ON
THE WEBINAR TODAY.

GREETINGS.

MAY I JUST GO AHEAD?

>> YOU SURE CAN.

ON THE BOTTOM LEFT-HAND SIDE
YOU’LL SEE AN ARROW POINTING TO
THE LEFT AND TO THE RIGHT.

RIGHT IS TO MOVE FORWARD.

>> TECHNOLOGY IS JUST SO COOL.

ALL RIGHT LET’S TRY IT AND SEE
WHAT HAPPENS.

OKAY.

THANK YOU SO MUCH.

SO I’M JOINED BY A NUMBER OF MY
COLLEAGUES HERE IN MINNESOTA.

ONE OF THEM ALREADY HAD TO LEAVE
ACTUALLY FOR ANOTHER MEETING,
BUT WE’RE JUST GOING TO TALK FOR
A LITTLE BIT.
SOME OF OUR COMMENTS WILL ECHO YOUR STARTING SLIDE, THE INTRODUCTORY SLIDES. AND THEN WE’LL BUILD ON WHAT MICHAEL SAID. SO WE HAVE A REGISTRY IN MINNESOTA. YOU’LL SEE LESLIE’S NAME FIRST. DR. SEYMOUR WITH ME. DAVE AND CAROL SMITH FROM THE MEDICAL CENTER ARE HERE. AND MY COLLEAGUE GAIL JUST HAD TO LEAVE. SHE’S WITH OUR, PART OF OUR TEAM WITH OUR DEPARTMENT OF EMPLOYMENT AND ECONOMIC DEVELOPMENT. AND THEN I THINK MY COLLEAGUE DAVID KING WAS OUR MINNESOTA PREEN -- BRAIN INJURY ALLIANCE IS ON REMOTELY AND YOU MAY HEAR HIM AT MOMENTS AS WELL. WE’RE GOING TO TALK ABOUT A REGISTRY. AND THE PURPOSE IS, YOU’LL HEAR
FOLKS ACROSS THE NATION SAY IF YOU CAN CHOOSE ONE OR THE OTHER, DO IT.
AND MAYBE TRY NOT TO DO BOTH. BECAUSE DOING BOTH CAN HAVE BOTH SURVEILLANCE AND A REGISTRY CAN SOMETIMES HAVE THEIR OWN CHALLENGES. BECAUSE THEY HAVE DIFFERENT APPETITES. AND MICHAEL JUST DID A SUPERB JOB OF DESCRIBING A SURVEILLANCE SYSTEM AND HOW THAT FUNCTION OVERALL. SO OUR LEGISLATURE HOWEVER WHEN THEY TOLD US TO DEVELOP THE REGISTRY, SAID YOU KNOW WE’VE HEARD WHAT YOU SAID, MARK, ABOUT UNDERSTANDING HOW BIG A PROBLEM TRAUMATIC BRAIN INJURY AND SPINAL CORD INJURY ARE IN MINNESOTA. SO WE WANT YOU TO DO BOTH. WE WANT YOU TO DEVELOP THE BEST REGISTRY IN THE NATION, AND
Also, collect data so that you can look at the population and describe the epidemiology of traumatic brain injury. So you'll see in the next slide in a moment, but the over-arching purposes for our registry is one, to provide timely service information. Right near the end of the talk, and I think Rebecca you said maybe just for about, I need to be done in 45 or 53 minutes, something like that. So I'll really go quickly here. What we want to do is make a difference in outcomes. Our legislature said okay we've heard you advocates and we've heard you folks in public health, and human services, talk about people who are being discharged from acute care hospitals and they're falling through the cracks.
THEY'RE NOT BEING ABLE TO EITHER HOLD THE JOBS THAT THEY DID HAVE, FAMILIES ARE FALLING APART.
SOME ARE ENDING UP BACK IN JAILS OR PRISONS.
THERE ARE STRUGGLES WITH SCHOOL.
AND THE LEGISLATURE SAID OKAY WE HEAR YOU AND LET'S SEE IF WE CAN MAKE A DIFFERENCE IN IMPROVING OUTCOMES.
THE SECOND MAIN PURPOSE WAS TO DESCRIBE THE EPIDEMIOLOGY OF TBI IN MINNESOTA AND TO DO PREVENTION.
I THINK MICHAEL REALLY COVERED THAT AGAIN IN AN EXCELLENT MANNER.
WE HAVE BEEN CHARGED TO HELP REDEFINE THE UNACCEPTABLE.
THAT'S PART OF KIND OF THE THIRD PURPOSE THAT WE'VE ADDED TO OUR REGISTRY.
YOU CAN SEE IT UP CLOSE WHEN YOU DOWNLOAD THE SLIDES LATER THIS
WEEK.

BUT THE LEGISLATIVE, IT'S ONE
PART OF THE LEGISLATION THAT
AUTHORIZES US TO BUILD OUR
SPINAL CORD INJURY REGISTRY.
YOU'LL SEE THE TWO PURPOSES IN
THAT LANGUAGE.

OKAY.

SO MOST OF THE MINUTES JUST IN
SUMMARY RIGHT HERE, REBECCA
ASKED THAT I TALK ABOUT.

SO HOW DOES THIS REGISTRY
FUNCTION.

WELL IN MINNESOTA ALL OF OUR
ACUTE CARE HOSPITALS REPORT
ANYONE WHOSE DISCHARGED WITH A
DIAGNOSIS OF TRAUMATIC BRAIN
INJURY.

SO THE MEDICAL RECORDS CODERS
LOOK AT THE WORDING THAT COMES
TO THEM FROM THE DOCS AND THE
NURSES.

AND THEY ARE THE CODING
SPECIALISTS, SO THOSE ACROSS THE
STATE ASSIGN THE CODES, THEY
PICK UP ON THE WORDS THAT ARE USED.
SO WHETHER IT'S CONCUSSION SUBARACHNOID HEMORRHAGE, THEY HAVE THE CODE FOR THAT.
AND OUR CODERS ASSIGN THE CODE AND THEN ACCORDING TO THE LEGISLATIVE MANDATE, WE BUILT THE SYSTEM FOR THEM TO REPORT.
WHEN WE FIRST STARTED IN 1991, IT WAS ON PAPER.
THERE WERE TWO HOSPITALS EVEN THEN THAT SUBMITTED AN EXCEL FILE WITH THEIR CASES, BUT MOST OF THE HOSPITALS IN MINNESOTA REPORTED ON PAPER.
AND WITHIN NIGHT EVEN A YEAR, OUR LARGER TRAUMA CENTERS WERE SAYING MARK, DEVISE ANOTHER WAY OR MAYBE YOU'LL EXPERIENCE FIRST HAND THE TBI -- NO, THEY DIDN'T QUITE SAY THAT.
IT WAS AN ONEROUS KIND OF SYSTEM.
AND SO WE WORKED TO DEVELOP AS
ELECTRIC A SYSTEM AS POSSIBLE.
AND IT'S STILL, THERE ARE THOSE
THAT STILL SAY MARK WHO IS TOO
MUCH WORK.
IF NOT, IT'S EASY AS IT SHOULD
BE.
BUT FOR THE MOST PART IT'S
GOTTEN MORE SMOOTH AS WE'VE
WORKED THE KINKS OUT.
SO HOW DID THEY REPORT AGAIN.
MOST REPORT ELECTRONICALLY.
THEY HAVE BY STATUTE UP TO 60
DAYS AFTER DISCHARGE TO REPORT.
OUR MEDIAN IS PROBABLY IN THE
ORDER OF 83 DAYS, SO WE DON'T,
WE TRY TO OFFER AS MANY CARROTS
AS POSSIBLE.
WE TRY TO HELP THE DATA SING.
MARK AND JOHN WHOSE NAME YOU'LL
SEE AT THE END AND WHO MIGHT
ACTUALLY SLIP IN TO THE MEETING
AS WE'RE GOING ALONG HERE, IS
OUR LEAD EPIDEMIOLOGIST IN TERMS
OF TRANSLATING DATA INTO MUSIC
THAT STATE AGENCIES AND ALL OF
OUR PARTNERS CAN SING WITH.
WHAT DO THEY REPORT?
AGAIN, THEY REPORT ALL THE
INPATIENT ADMISSIONS.
SO OUR ED DATA, WE COLLECT IN A
MANNER VERY SIMILAR TO MICHAEL'S
IN NEW YORK STATE.
THAT'S THROUGH OUR HOSPITAL
ASSOCIATION AND OUR HOSPITAL
DISCHARGE SYSTEM.
WE DON'T HAVE IDENTIFIERS ON OUR
ED DATA.
WE DO HAVE THE CONTACT
INFORMATION ON IN-PATIENT
BECAUSE THAT'S HOW WE THEN
CONTACT FOLKS AS YOU'LL SEE IN
JUST A MOMENT.
THE DATA ARE USED TO DRIVE
PREVENTION EFFORTS, POLICY
CHANGES, ORGANIZATIONAL PRACTICE
CHANGE.
AND THE DATA ARE USED TO, FOR US
TO CONTACT FAMILIES WHO HAVE HAD
A TRAUMATIC BRAIN INJURY.
NOW, WE'VE TRIED TO SPEND SOME
TIME MAKING SURE THAT THE DATA ARE OF HIGH QUALITY.
AND SO WHAT WE DO IS WE ABSTRACT A SAMPLE OF CASES.
WE'VE NOT SELECTED A SAMPLE THIS YEAR.
SULTLY SO UP -- ABSOLUTELY UP TO TWO YEARS AGO WE'VE BEEN IN THE FIELD ABSTRACTING BUT THE PLAN IS TO TRY TO ABSTRACT THE SAMPLE YEARLY.
WE GO OUT AND WE REABSTRACT THE DATA THAT HOSPITALS HAVE SUBMITTED SO THAT WE'RE MAKING SURE THAT THE DATA THAT WERE REPORT TO US ARE THE SAME AS WHAT WE FIND WHEN WE GO BACK OUT AND REABSTRACT.
SO THAT ALLOWS US TO DEVELOP SOME QUALITY MEASURES OF THE DATA.
I THINK I'LL SKIP RIGHT OVER THIS SLIDE BECAUSE MICHAEL JUST DID A SUPREME JOB OF DESCRIBING THE TBI EPIDEMIOLOGY.
SO I'LL TALK JUST FOR A FEW
MINUTES ABOUT RESOURCE
FACILITATION.
SO WHY DO THE REGISTRY?
AGAIN AS WE NOTED IN THE
BEGINNING, IT'S TO GET AT
IMPROVING OUTCOMES.
AND RESOURCE FACILITATION IS
THAT PROCESS THAT A NUMBER OF
STATES NOW ARE USING, THAT IS
THIS PARTNERSHIP AS WE SEE IN
THE DEFINITION, IT HELPS PEOPLE
AND COMMUNITIES CHOOSE, GET AND
KEEP INFORMATION, SERVICES AND
SUPPORTS TO MAKE INFORMED
CHOICES, AND MEET THEIR GOALS.
IT'S THE WAY OF CONNECTING THOSE
WHO HAVE HAD A TBI WITH THE
SERVICES THAT THEY NEED IN ORDER
TO DO BETTER.
WHETHER IT'S DO BETTER IN NEW JOB
OR DO BETTER IN FAMILY OR A NEW
SCHOOL.
THEN SOME BRIEF DATA ON HOW
WE'VE GONE ABOUT CONDUCTING AND
IMPROVING RESOURCE FACILITATION.

WHAT WE FOUND THE LAST DOT ON THIS SLIDE IS OF NOTE.

WHAT WE FOUND IS THAT THE COMBINATION OF SENDING A LETTER, A HOSPITAL BEFORE A PATIENT'S DISCHARGE, MAKING A REFERRAL OR IN THE PACKET OF INFORMATION THAT GOES WITH THE PATIENT, GIVING THE RECOMMENDATIONS OR REFERRAL TO THE MINNESOTA BRAIN INJURY ALLIANCE.

THE TELEPHONE OUTREACH TO THE FAMILY, PROVIDING E-MAIL AND YOUR WEB LINKS, THE WHOLE KIND OF THIS COMBINATION SYSTEM IS WHAT WORKS BEST.

AND AGAIN, IT'S WITH HAVING FOLKS ACROSS THE WHOLE AGE SPECTRUM, WE NEED A VARIETY OF STRATEGIES TO TRY TO REACH PEOPLE WITH INFORMATION THAT THEY NEED.

YOU'LL SEE THAT GREAT STATE IN THE CENTRAL NORTH PART, THE
INTRICATE DESIGN.

AND AGAIN, WE’LL JUST SCAMPER THROUGH HERE SO THAT REBECCA WE CAN TURN THIS BACK TO YOU.

WE SERVED ROUGHLY BETWEEN 13 AND 15 THOUSAND PEOPLE A YEAR WITH RESOURCE FACILITATION.

AGAIN, WE DON’T HAVE THAT MANY NEW CASES BUT ONCE SOMEONE STARTS THE PROCESS, WE SEE ABOUT 5,000, 5500 FOLKS WHO ARE DISCHARGED FROM THE IN PATIENT SETTING EACH YEAR IN MINNESOTA.

NOT ALL OF THOSE WANT TO PARTICIPATE IN RESOURCE FACILITATION, SOME SAY MAN, I’VE GOT MY ACT BACK TOGETHER, I DON’T NEED ANYTHING ELSE AND THING ARE GOING ALONG JUST FINE.

SO ONE OF THE THINGS, AND MICHAEL I THINK YOU MAY HAVE STARTED TO ADDRESS THIS AS WELL ABOUT THE RELATIONSHIP BETWEEN INCOME AND BRAIN INJURY.

SO MY COLLEAGUE LESLIE TOOK A
LOOK AT THE MEDIAN INCOME BY ZIP CODE.

AND WHAT WE FIND IS FOR BOTH EMERGENCY DEPARTMENT TREATED TRAUMATIC BRAIN INJURY AND IN PATIENT HOSPITAL ADMISSIONS, THIS INVERSE RELATIONSHIP BETWEEN INCOME AND RISK OF OUR EXPERIENCE WITH TRAUMATIC BRAIN INJURY.


OVER TIME, YOU'LL SEE OUR, THIS IS FOR THOSE IN THAT NEXT AGE COHORT ABOVE ME, TBI MORTALITY RATE BY YEAR CONTINUES TO INCREASE.

AND SO NEXT YEAR, I WILL BE PART OF THAT 55 PLUS COHORT.

IN CLOSING, SO GETTING BACK TO
OUR OUTCOMES.

OUR COLLEAGUE JIM WHO ADVOCATED
MINNESOTA FOR INDIANA, JIM HAS
REALLY HELPED TO DRIVE OUR
THINKING ABOUT HOW WE UNDERSTAND
IMPROVING OUTCOMES.

AND FOR TOAST -- FOLKS WHO HAD A
BRAIN INJURY.

HE SUGGESTED WE ASK THESE
QUESTIONS WHEN WE TALK TO FOLKS
BY PHONE OR BY LETTER.

MARK, DO YOU USE SERVICES THAT
HELP YOU DO BETTER.

OR, MARK, DO YOU NEED SERVICES?
YOU MAY NOT BE CURRENTLY GETTING
THEM, BUT DO YOU NEED THEM.

OR MARK, HAVE YOU BEEN TOLD BY
YOUR DOCTOR, BY YOUR FRIEND, PIE
-- BY YOUR NEIGHBOR, BY YOUR
FAMILY THAT YOU NEED SERVICES.

THESE ARE A WAYS TO KIND OF GET
A HANDLE ON IS THERE A GAP RIGHT
NOW THAT I CURRENTLY NEED.

SO WE CALL THAT OUR MALLECK BALL
TO UNDERSTAND TBI PREVALENCE.
THAT’S HOW MANY CASES ARE OUT THERE IN THE STATE AT A GIVEN TIME.

AND I THINK THE, OH, A LISTING OF SOME OF MY COLLEAGUES.

I DIDN’T PUT ALL OF OUR E-MAIL ADDRESSES ON, THOSE OF US IN THE ROOM ARE THOSE SCATTERED ACROSS THE MINNESOTA DIASPORA BUT THANK YOU SO MUCH, I DIDN’T TAKE ALL 53 MINUTES, REBECCA BUT HOPEFULLY I DID IT IN ABOUT MAYBE 10 OR SO. HOPEFULLY THAT WAS OKAY.

LET ME JUST, BEFORE YOU MUTE US HERE, LET ME JUST LOOK TO MY COLLEAGUES. LESLIE, CAROL ANN, DAVID, ANYTHING ELSE FOR THE NATION TO HEAR ABOUT OUR REGISTRY FUNCTIONS IN MINNESOTA OR IN DISTINCTION TO THE SURVEILLANCE SYSTEM.

>> I'LL HOP IN.

THIS IS CAROL ANN SMITH -- WE
ARE THE LARGEST LEVEL ONE TRAUMA CENTER IN MINNESOTA AND HAVE BEEN INVOLVED WITH GETTING INFORMATION TO THE REGISTRY FOR MANY YEARS.

AND WE WERE ALSO THE PILOT, ONE OF THE PILOT HOSPITALS FOR RESOURCE FACILITATION.

ONE OF THE THINGS THAT MARK DIDN’T SHOW IS SOMETHING CALLED MIDAS WHERE YOU CAN GET ON-LINE AND LOOK UP ALL OF THESE STATISTICS IN A REALLY USER FRIENDLY WAY.

AND I AM ON MIDAS ALL THE TIME WHERE I CAN FIND OUT A MECHANISM OF INJURY.

I CAN LOOK BY AGE, BY GENDER, BY COUNTY, BY STATES.

AND IT'S REALLY HELPFUL TO ME AS WE'RE DOING PLANNING WITHIN THE TRAUMATIC BRAIN INJURY CENTER AT A LEVEL 1 TRAUMA HOSPITAL.

>> THANKS CAROL ANN.

IN MY REDRAFT I HAD SOME SEVERAL
SLIDES IN THERE THAT WALKED US THROUGH THE TBI WALK AT MIDAS BUT I TOOKED THEM OUT. OKAY, THANK YOU. WE'LL BE QUIET AND/OR ANSWER QUESTIONS. >> GREAT, THANK YOU SO MUCH. THAT WAS AN EXCELLENT PRESENTATION. THAT WAS REALLY EXCITING TO SEE. ALL RIGHT. WHAT WE'RE GOING TO DO NOW IS WE'RE GOING TO UNMUTE EVERYONE'S PHONE LINE AND I'M GOING TO OPEN UP THE FLOOR FOR DISCUSSION. I'VE SEEN A COUPLE QUESTIONS COME THROUGH. IF YOU ARE VERY NOISY IN YOUR AREA AND YOU'RE NOT SPEAKING, I WOULD LIKE TO ASK YOU TO SELF MUTE. BUT OTHERWISE I'M GOING TO GET THE BALL ROLLING WITH -- THE CHAT HOW YOU GET AROUND HIPPA ISSUES FOR HOSPITALS.
THERE WAS A DIALOGUE IN THE CHATBOX.

IF YOU'RE NOT COMFORTABLE ASKING A QUESTION OUT LOUD, PLAIZA FEEL FREE TO ASK THE QUESTION IN THE CHATBOX AND I'LL READ IT OUTLOUD.

MARK WOULD SOMEONE FROM YOUR TEAM LIKE TO TALK ABOUT HIPPA ISSUES.

>> SURE, I'LL GO AHEAD AND JUMP IN TO START WITH.

THAT'S BEEN A LIVE QUESTION AND ACTUALLY WHEN SOME OF OUR, SOME OF THE LAWYERS FOR HOSPITALS ARE REALLY, THEY DRIVE AND PUT THAT QUESTION AT THE FOREFRONT OF THE HOSPITAL CEO'S OR THE DOCS.

WE STARTED OURS IN 1991 WHICH WAS REALLY PREHIPPA, AT LEAST PRE THOSE WORDS WE WERE THANK YOUFUL ABOUT PRIVACY AND THINGS LIKE THAT.

HOSPITAL HISTORICALLY HAD PRIVACY LAWS.
BUT BECAUSE THE LEGISLATURE PUT THE COMBINED CLAUSE OF UNDERSTANDING THE PUBLIC HEALTH IMPACT OR THE PUBLIC HEALTH SURVEILLANCE, THE POPULATION IMPACT FOR BRAIN INJURY AND SPINAL CORD INJURY, THAT ALLOWED US TO USE THE PUBLIC HEALTH EXEMPTION IN HIPPA. BECAUSE OF THAT THE HIPPA PROVISIONS DON'T APPLY TO THE HEALTH DEPARTMENT AND IN FACT OUR LEGISLATION IS STRONGER. I MEAN OUR DATA COLLECTION AND PROTECTION IS STRONGER THAN THE HOSPITAL THEMSELVES CAN PROVIDE. SO THE DATA THAT THEY REPORT TO US ARE EXEMPT FROM THE HIPPA REQUIREMENTS. AND THEY ARE ALSO, WE CAN ASSURE THEM THAT WE WILL PROTECT THE DATA THEY REPORT TO US. BECAUSE THE DATA THAT COME TO THE MINNESOTA DEPARTMENT OF HEALTH ARE NOT SUBPOENAABLE.
WHEREAS A HOSPITAL-OWNED DATA
CAN BE SUBPOENNAED BY COURT.

>> I SEE THAT NORTH DAKOTA HAS
THEIR HAND RAISED.

DOES SOMEONE FROM NORTH DAKOTA
WANT TO SAY SOMETHING?

>> HI, MARK IT'S DIANA FROM
NORTH DAKOTA.

I HAVE A QUESTION ABOUT THE
AMOUNT OF DEDICATED FUNDS THAT
YOUR LEGISLATURE PUT TOWARDS THE
REGISTRY.

>> SURE.

WHAT THEY DID IN MINNESOTA WAS
THEY SAID WE'RE GOING TO HOOK
THIS TO THE FOLKS WHO DRINK AND
DRIVE AND LOSE THEIR LICENSE AND
HAVE TO PAY TO GET IT BACK.

AND SO INITIALLY, IT WAS A 5%
FEE, BUT THEN THEY CHANGED IT TO
A FLAT FEE.

SO NOW THERE'S A $50 SURCHARGE,
A $50 REINSTATEMENT FEE THAT'S
ADDED TO ALL OF THE COSTS
ASSOCIATED WITH GETTING ONE'S
LICENSE BACK WHEN ONE CHOOSES TO DRINK AND DRIVE IN MINNESOTA.

SO $50 ARE ADDED ON.

AND TWO YEARS AGO, THE LEGISLATURE INTRODUCED AN INSTALLMENT PLAN FOR THOSE WANTING TO REGAIN THEIR LICENSE.

BUT THEY SAID THAT THE DUI REINSTATEMENT FEE OR THE PARTS OF THE BRAIN INJURY HAD TO COME FIRST.

SO THE FIRST PAYMENT THAT COMES IN IN BUYING YOUR LICENSE BACK IS FOR THE BRAIN INJURY REGISTRY.

SO WHAT THAT AMOUNTS TO, TO GIVE YOU AN IDEA OF HOW MUCH WE DRINK AND DRIVE IN MINNESOTA, WE END UP GETTING ABOUT $1.2 MILLION A YEAR.

OF THAT $1.2 MILLION, 83%, IT'S SWEET, MAN.

IT'S 83% GOES TO OUR BRAIN INJURY ALLIANCE.

AND BECAUSE OUR BRAIN INJURY
ALLIANCE IS WHO DOES THE
HANDS-ON DAY TO DAY IN DEPTH
RESOURCE FACILITATION.
SO I SEND OUT A LETTER AND A
PACKET OF INFORMATION.
AND THEN TO EVERY PERSON WHO IS
DISCHARGED.
OR TO THE PARENT OR GUARDIAN IF
IT’S A CHILD.
BUT SO I TEND TO INTRODUCE
RESOURCE FACILITATION AND TALK
ABOUT WHAT’S COMING.
I INCLUDE A HANDOUT ABOUT SCENES
-- SIGNS AND SYMPTOMS OF
A CONCUSSION, WHAT TO WATCH FOR.
SOME CONTACT LISTS RANGING FROM
DEPARTMENT OF DEFENSE TO SOCIAL
SECURITY TO THE BRAIN INJURY
ALLIANCE.
AND SOME OTHER HELPFUL NUMBERS.
AND I USUALLY, I GET TWO
EXTREMES OF PHONE CALLS BACK.
MARK THANK YOU SO MUCH THIS HAS
HELPED ME AND MADE MY DAY.
AND THOSE WHO ARE REALLY TICKED,
MARK HOW DID YOU FIND OUT ABOUT THIS, WHO REPORTED ME.

USUALLY AFTER I EXPLAIN THE RATIONALE OF THE LEGISLATURE, AND WHAT WE ARE ALL ABOUT, MOST OF THE TIME THEY'RE OKAY. THERE'S BEEN A FEW TIMES WHERE THEY'VE HUNG UP ON ME STILL PRETTY HOT.

>> I'M STILL CURIOUS, SO 83% GOES TO THE BRAIN INJURY ALLIANCE.

WHAT FUNDS THE REGISTRY ITSELF, THE DATA COLLECTION?

>> SO THE 17% THAT'S LEFT ABOUT $200,000 OR SO THAT PAYS FOR PART OF LESLIE'S SALARY, A LITTLE BIT OF MINE.

SO WE'RE BROKEN UP. NONE OF US ARE A HUNDRED PERCENT FUNDED BUT WE HAVE A PART TIME PROGRAMMER.

WELL A FULL TIME PROGRAMMER BUT PART OF THE SALARY'S PAID FROM THIS, PART OF LESLIE'S SALARY IS
AN EPIDEMIOLOGIST.

SO WE'VE COBBLED TOGETHER
FUNDING SOURCES.

AND THIS PAYS FOR THE SYSTEM AND
THEN THE DATA ANALYSIS AND THE
SENDING THE LETTERS OUT AND
THINGS LIKE THAT.

>> ALL OF THE $50 THAT SURCHARGE
YOU WERE TALKING ABOUT IS FOR
TRAUMATIC BRAIN INJURY ETCETERA,
RIGHT.

>> YES, CORRECT.

>> THAT'S ASSESSED RIGHT OFF THE
TOP FOR A DUI.

>> YES.

>> DO YOU WORK IN TANDEM WITH
YOUR HUMAN SERVICES PEOPLE.

>> WE DO.

MOST OF THE TIME MARY PROBABLY
ON THE PHONE CALL FROM NORTHERN
MINNESOTA, SO WE WORK AND I SIT
ON THEIR ADVISORY COMMITTEE.

WE'RE PART OF THE PRACTICE.

IN FACT IN THE ROOM HERE CAROL
ANN AND DAVID ARE ALSO ON THE
PART OF THE HUMAN SERVICES TBI
ADVISORY COMMITTEE AND WE'RE
WORKING HAS NOT IN HAND WITH
THEM.

>> THANK YOU, MASH.

>> WE'VE GOT ABOUT FOUR MINUTES
LEFT.

I'M GOING TO ASK ONE MORE
QUESTION THAT JUST CAME UP AND
THEN I'M GOING TO SEND THESE
QUESTIONS TO OUR PRESENTERS AND
ASK THAT THEY RESPOND TO THEM TO
THE LIST SERVE WHEN THEY HAVE
TIME TO CATCH THEIR BREATH.

THE LAST QUESTION I'M ASKING IS
IF THERE'S A LAPSE IN TIME LIKE
60'S OF A DEATH MATCH BEFORE
SENDING LETTERS TO SURVIVORS.

THAT'S FROM ROSE BOY.

IF YOU'RE ON THE LINE AND WANT
TO CLARIFY YOUR QUESTION AT ALL,
PLEASE FEEL FREE TO.

>> IN OTHER WORDS, IF YOU'RE
SENDING LETTERS OUT TO SURVIVORS
WHO TELL THEM ABOUT SERVICES, IS
THERE A CHANCE THAT SOMEBODY MAY HAVE DIED AND YOU'VE SENT A LETTER TO SOMEBODY WHO HAS DIED FROM THEIR INJURIES.

>> THERE IS, YES.

HI ROSE, GOOD TO HEAR YOU.

>> HI.

>> HI.

THERE IS A CHANCE.
WE TRY, WE'RE HOT LINKED, WE HAVE ELECTRONIC DEATH RECORDS, AND SO DEATH RECORDS ARE FLOWING IN TO OUR UNIT ON AN AS THEY COME INTO THE DEPARTMENT BASIS.
OUR PROGRAMMERS SET IN A HOT LING SO AS THEY COME INTO THE DEPARTMENT OF VITAL RECORDS THEY ALSO COME TO US.
ONCE A WEEK WE DO THE PROCESSING OF HOSPITAL DATA THAT'S COME IN.
SO WE'VE RUN THAT AS OF THAT MOMENT IN TIME, WE'VE RUN THOSE RECORDS AGAINST THE DEATH RECORDS BECAUSE IT'S LIKELY ESPECIALLY WITH THAT DELAY OF
60-80 DAYS THAT SOMEONE HAS
PARISHED.
AND UNFORTUNATELY, SO WE'VE
TRIED TO REDUCE THE RISK OF A
LETTER GOING TO SOMEONE WHO JUST
DIED.
IT STILL HAPPENS BUT IT'S A RARE
EVENT NOW WHEREAS IN THE EARLY
90'S WHEN I WAS STARTING THIS,
THE HEART BREAKING CALLS WERE,
WHEN AN ADULT DIES OR YOUR
PARENTS OR GRANDPARENTS, THERE'S
STILL SADNESS BUT THE CALLS I
GOT FROM A MOM OR DAD WHO SAID
MARK, WE JUST BURIED OUR
DAUGHTER OR OUR SON.
AND THAT WAS LIKE OH MAN,
THERE'S GOT TO BE A WAY TO DO
THIS.
SO SHORT ANSWER, OR LONG ANSWER
TO THE SHORT QUESTION, YES, WE
DO THE HOT LINK TO TRY TO REDUCE
THE RISK AND WE'RE DOING A LOT
BETTER AT IT.
>> THANKS SO MUCH.
ALL RIGHT, WE HAVE ONE MINUTE
LEFT SO I JUST WANTED TO SAY A
REALLY SINCERE THANK YOU TO BOTH
MICHAEL AND MARK.
THEY REALLY CAME IN AT THE 11
HOUR AND I COULDN’T BE MORE
THANKFUL FOR PUTTING TOGETHER
SUCH AN AMAZING PRESENTATION AND
HELPING KNOW SILL -- FACILITATE
SUCH A GREAT CONVERSATION.
IF YOU HAVE ADDITIONAL QUESTIONS
YOU CAN E-MAIL THEM TO ME AND
I’LL E-MAIL THEM TO MICHAEL OR
MARK AND ASK THEM TO RESPOND TO
THE LIST SERVE OF THOSE
QUESTIONS AND ANSWERS SO WE CAN
GET A DIALOGUE GOING THERE AS
WELL.
IF YOU WANT TO E-MAIL THEM TO ME
DIRECTLY AT RHUNT@DEC.ORG.
OR YOU CAN MAIL IT TO -- THAT'S
ALSO ON OUR WEBSITE.
WE'LL HAVE OUR NEXT MEETING ON
WEDNESDAY NOVEMBER 6 AT 3:00 PM
EASTERN TIME.
IT SHOULD BE ON YOUR CALENDARS.
AND THAT'S ALL THE TIME WE HAVE
TODAY.
I WANT TO THANK YOU SO MUCH FOR
YOUR PARTICIPATION AND I LOOK
FORWARD TO TALKING TO YOU AGAIN.
TAKE CARE.

>> THANK YOU.
>> THANK YOU.
>> THANK YOU.
>> THANK YOU.